

A Publication of Harbor Hospice

Touching Lives™

Holding Hands. Holding Hearts.



Telling Your Story Your Way

**Why You Need
Someone Who
Will Really Listen**

**The Gift of
Three Wishes**

**Finding Joy
in Celebrating
Time Together**

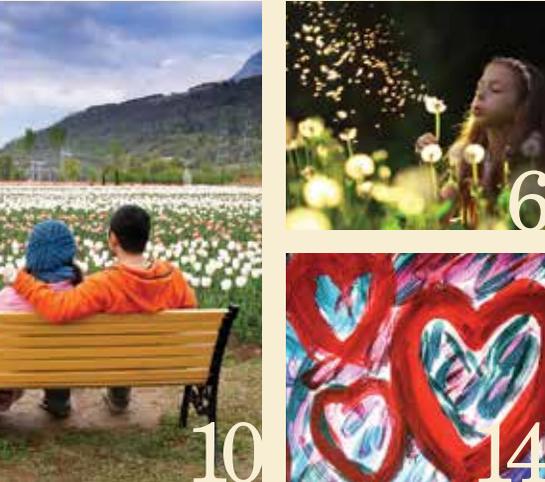
**Spiritual Care
Conversations**

HARBOR
HOSPICE
Your Journey. Your Terms. Our Expertise.

FEATURE ARTICLE

10 Why You Need Someone Who Will Really Listen

By Paula Spencer Scott



CONTENTS

4 Gifts from the Heart By Susan Newhof

LIVE WELL

5 Finding Joy in Celebrating Time Together By Bob Calandra

CAREGIVER'S CORNER

6 The Gift of Three Wishes By Marlene A. Prost

HELPING HANDS

8 Making Decisions Makes Life Easier By Marlene A. Prost

MEMORABLE MOMENTS

9 Telling Your Story Your Way By Jason Wright

FRIENDS & FAMILY

14 The 'Right Way' to Love By Paula Spencer Scott

SPIRITUAL SUPPORT

15 Spiritual Care Conversations By Dr. Harold Koenig

17 Living Our Mission, Our Foundation

18 A Father's Walk Through Grief By Susan Newhof

Welcome to *Touching Lives*



Dear Friend,

Harbor Hospice has a rich history of caring for patients and families living with life limiting illness and coping with grief.

Over the last thirty-four years we have served thousands of families along the west Michigan lakeshore. Through our *Touching Lives* magazine we want to share all that Harbor Hospice has to offer with the hope that patients and their caregivers will access our care sooner when it can be of the most help. We want patients to understand how focused we are in helping them to meet their goals; how we coordinate their care to support them and their caregivers; and that we bring that care to their bedside wherever they call home.

In this issue of *Touching Lives*, you'll read about our patient, a mother and grandmother, who is determined to give her family the gift of tradition and shared memories. A father's story of the loss of his daughter provides powerful testimony to the comfort and help for healing available through our grief support program.

Our feature article *Why You Need Someone Who Will Really Listen* gives helpful insight around ways to be a "powerful listener" and being attuned to what a friend in crisis might want to share. Articles by national experts share stories of patients and their caregivers finding joy and meaning in the midst of illness by giving voice to final wishes for their time together.

As our mission includes care for the poor and those in need of financial assistance, we also share the goal of our Harbor Hospice Foundation to ensure that our services are available to all without regard for ability to pay. We invite you to consider including the Harbor Hospice Foundation in your annual and estate plan giving.

We understand the stresses and uncertainties surrounding care at the end of life. We have learned that there is so much that hospice can do to make a difference. We can bring comfort. We can offer hope for time to say the important things. And most importantly we'll start by asking "What's important to you and how can we help?"

Warm Regards,

A handwritten signature in cursive script that reads "Mary Anne Gorman".

Mary Anne Gorman
Executive Director



Harbor Hospice

1050 W. Western Avenue, Suite 400
Muskegon, MI 49441

1.800.497.9559

HarborHospiceMI.org

Gifts *from* the Heart

by Susan Newhof

I don't think there's ever been a time when there weren't little kids around me," Debbie Lemieux says from the living room of the home she shares with her daughter, Leesa; son-in-law, Chris; and their four children. Her eyes twinkle when she talks. "I love my family. We have a great time together!"

Debbie's been close to her children and grandchildren throughout their lives. She worked part time so she could care for them and attend their school events, and she laughs when she tells how popular she was when she distributed candy for the Hershey Company and always had a ready supply.

"Our house was the place to hit on Halloween!" Leesa chimes in.

In 2010, Debbie was diagnosed with ovarian cancer, and her life became an unexpected patchwork of surgeries, chemotherapy, and complications. After treatment and four years of remission, it came back. Debbie chose chemo again because

she had a new grandchild and it seemed the right thing to do. She had a bad reaction to the drugs, followed by remission. And the cancer came back. Again.

"I realized I had to choose between *quantity* of life and *quality* of life," Debbie recalls. "I asked myself what I wanted to do and what would be good for me. I didn't want to be so sick that I couldn't enjoy my family."

She also decided to leave a crumbling marriage and asked about living with Leesa's clan.

For Leesa, the answer was an easy yes! "She's always been my best friend," Leesa says, smiling across the room at her mother. "We just look at each other and we know what each other is thinking!"

The family bought a larger home to accommodate everyone and moved in February. And they called Harbor Hospice.



"I spent one day upstairs letting this soak in," says the pixie-like grandmother, who seems as full of life as the busy grandkids and two puppies running in and out of the living room. "After that, I didn't give it much thought. Hospice made life easier for me. I was tired of going to doctors and hearing the same words every time. Now, I can be at home and comfy. The Hospice staff comes to our house to see me."

With memory-making in mind, Leesa and Pamela Wingard, a grief counselor for Harbor Hospice, applied to the Dream Foundation and requested a trip to Disneyland for the whole family, including Debbie's daughter and son-in-law, Stacy and Cameron, and their daughter, Taylor. "Cinderella,"
(continued on next page)

Leesa explains, “has always been my mom’s favorite princess!”

The wish was granted, but there was a hitch. “Mom didn’t have the energy for it,” says Leesa. “We wanted something she would be able to do with us and not be sitting on the sidelines. Then we thought about Christmas. Mom has a tradition of making sure the kids have a really special Christmas. Every year at the holidays, we will gather in front of our fireplace, and we want memories of sharing quiet times there with her.”

Unfortunately, the fireplace was old and unattractive, so the Dream Foundation approved the family’s request to update it in lieu of the trip.

“It’s a wood-burning fireplace,” Debbie says, running her hands over the mantle where the children’s stockings will hang on Christmas Eve. There will be presents, too, that she already purchased, including one of her favorite traditions — new pajamas for everyone. “We love the warmth of this fireplace,” she adds, “and we’ve already had fun making s’mores and hotdogs!”

“We’ve been able to make memories here with mom,” says Leesa, “and when she can’t go upstairs anymore, this room will be hers.”

Motivated, in part, by the loss she felt when her own mother died, Debbie selected seven books and is recording herself reading them out loud — one for each grandchild and her daughters. She ordered a bracelet and charm with “Love Nana” on it in her handwriting for each granddaughter and a watch for grandson, Bryce. She’s also writing a letter to each family member.

“I took care of my mother, but we didn’t talk much about how we felt about each other,” she remembers. “It would have been nice to have a note from her or something tangible that I could hold on to after she was gone. But there was nothing.” Debbie is doing it differently.

Life for this blended family is full of giggles and hugs, long talks, quiet moments, and playtime. Debbie cherishes simple things like joining everyone at the breakfast table,



One more gift to give:
**Debbie has donated her
 body to Med Cure so it
 can be used for research.**

dancing with her grandchildren in the evening, and attending Taylor’s high school graduation. Chris’s mother and sister stay with Debbie when Leesa and Chris are working, and when Debbie is resting, the children often go upstairs to check on her and snuggle.

“Hospice helps make it possible for Debbie to be at home and in the company of those she cares about most,” says Pamela. “They give her affirmation of life, of who she is, and what she means to them. They all have something to give each other and something to gain, even the youngest.”

Debbie agrees. “This isn’t hard for me,” she says, happily hugging toddler Joslynn at her knee and fielding questions from four-year-old Bella. Lauren is nearby playing with the puppies and Bryce isn’t far. “I have a very special family. I’ve lived my life with humor, and I’m going out with humor!” ❄️

Finding Joy

in Celebrating Time Together

Joyfulness isn't denial; it's defiance of difficult realities.

By Bob Calandra

Dave Caperton lives a joyful life. For the past 20 years, the former teacher turned author, comedian, and speaker has spent his days spreading the word about joyfulness.

He's not talking about that feeling of well-being and pleasure we associate with happiness. He's talking about that meaningful spiritual awareness of being connected to something larger than ourselves at end of life.

Like most 57-year-olds, he has lived through his share of difficult, life-changing moments, among them having his uncle, mother, and father-in-law enter hospice care in one five-week span.

"Suddenly I got a lot of exposure to hospice facilities, hospice in-home care, hospice workers and I've said ever since, we are on sacred ground," he says. "This was hard but it was a privilege to see how people could care so much, how they could give dignity."

Finding joyfulness at the end of a loved one's life isn't easy. Yet it was during those days that Caperton saw joyfulness in action. He watched family members, including those in care, celebrate their time together. Even during the most difficult challenging moments, people were still able to express their gratitude for being together.

And yes, Caperton says, there were tears but there was way more humor and laughter.

"I think it is a critical mistake not to give yourself permission to use humor when someone is in hospice", he says. "It is part of the healing and the celebration of life that you are there to share."

While his mother was in hospice it wasn't unusual for family members to gather around her bed and trade tales and laugh at stories from their shared past. The family sang
(continued on page 16)





The Gift of Three Wishes

Honoring personal requests creates positive memories

By Marlene A. Prost

For four days last spring, Bill Morrell's family and closest friends gathered at his bedside in the intensive care unit to say goodbye and to celebrate his life.

When Bill, 69, finally succumbed in the early morning hours, they encircled him, holding hands, as a nurse took one last photograph as the final image of their beloved father, grandfather, brother and friend.

The Morrell family made it through their darkest hour with the support of the ICU staff at St. Joseph's Healthcare in Hamilton, Ontario, and the hospital's unique Three Wishes Project.

The Three Wishes Project was introduced in 2013 to grant three wishes to patients in the ICU who are in their final days. If a patient cannot express herself, the family will make the wishes. The wishes are simple, but give the patient and family some peace of mind while celebrating a life's journey and creating final memories.

The Morrell family asked for a private room for their family to be together in the ICU; to keep Bill on life support until his brother and sister flew in from Australia; and for a last photograph when life support ended.

"The [staff] were so compassionate and respectful. They wanted to know him as a person. It just helped, knowing he died in such a loving and caring place and knowing they wanted to make the best out of the worst situation," said Melanie Wolfe, Bill's daughter, whose mother passed away nine years ago.

In their private room, family and friends were able to visit and reminisce about his childhood, his career at Nelson Steel and his passion for drag racing. The ICU staff got to know Bill through their stories and presented the family with a computer-generated Word Cloud to commemorate his life and personality [see sidebar].

The Three Wishes Project was initiated by Deborah Cook, MD, a physician in St. Joseph's ICU, to personalize and

humanize the dying patient's experience. What began as a two-year study has continued to help 73 families.

"We developed this project to try to bring peace to the final days of critically ill patients and to ease the grieving process. For the patients, we wanted to dignify their deaths and celebrate their lives; for family members, to humanize the dying experience and create positive memories; and for clinicians, to foster patient and family-centered care," explained Dr. Cook, a professor of medicine and clinical epidemiology at McMaster University's DeGroot School of Medicine.

Dr. Cook found that families made five types of requests:

- Humanizing the environment. Examples are a rock-and-roll sing-along, Scottish bagpipe music, a favorite TV channel, flowers and mementos.
- Personal tributes, like a tea party, tree planting or park bench in memoriam, and a last family dinner.
- Reconnecting with family by locating a lost relative, a pet visit or Skype reunion.
- Rituals and observances such as renewal of wedding vows, a bedside wedding and birthday celebration.
- Paying it forward with charitable giving and organ donation.

One dying patient was reunited with an estranged son. And one mother's wish was to lie with her dying son when he passed away, as she had at his birth.

The experience of granting final wishes has moved the health caregivers as well. One nurse said: "This project does force everyone to really look deep inside at ... how they ... might feel about end-of-life. This is putting the absolute human side [into] the whole experience. I think this project is so powerful."

For Melanie, the Three Wishes Project and the support of the ICU staff helped the family cope with their grief by honoring her father's life.

"I can't change what happened. But being in the ICU, I wish everyone's experience was like that, that they could be shown this respect and compassion. If everyone had the opportunity we had, it would make it easier to say goodbye." ❁

loved together
hard-worker family laughter
togetherness loving-husband
thoughtful innovator man-of-integrity
joy friend Nautilus fish father
memories supervisor Nelson Steel
drag-racing car-collector

The Word Cloud: A Lasting Memory

We have many ways to capture family memories, from photo albums to DVDs.

The Word Cloud is another, moving way to permanently honor a loved one's footprint in life. It is a computer-generated collage of individual words that capture a person's personality and passions, and what they mean to those they leave.

Melanie Wolfe keeps a Word Cloud commemorating her late beloved father, Bill Morrell, on her fireplace mantel. It was a gift from the ICU staff that cared for him last spring at St. Joseph's Healthcare in Hamilton, Ontario.

As part of the hospital's unique Three Wishes Project, the staff sits with the families of dying patients, listens to their stories and memories, and composes an individualized Word Cloud.

"The Word Cloud encompasses everything he did. He was an avid drag racer, a supervisor at Nelson Steel. He collected cars. And Nautilus was his pet fish," Melanie said. The Word Cloud also recalls Bill Morrell as a "man-of-integrity," "innovator" and "loving-husband."

"It brought closure because of the way we were treated. The [staff] were so compassionate and respectful. They wanted to get to know him as a person."

Making Decisions Makes Life Easier

*Know what a loved one wants
and put it in writing*

By Marlene A. Prost

Calm music floats through a room. Familiar faces surround the bed. Loving memories are told and retold.

These are some ways a family creates a comfortable environment for their loved one's last days.

There is another way that a family can give their dying loved one peace of mind. That is by discussing and resolving, as early as possible, any choices about medical care, funeral arrangements and settlement of affairs that can arise near the end of life.

When a family knows what their loved one would want done — and it is put in writing — a dying patient can feel assured that her last wishes will be fulfilled. A person in her last days may appreciate being asked and having some control over her own destiny. And family members don't have to worry about making choices under duress at the last minute, without knowing what their loved one would have wanted.

Here are three areas where planning ahead, and putting decisions in writing, can clarify a loved one's wishes.

1. Last will and testament. Many Americans put off writing a will. Yet having a will gives you control over what happens to your possessions. It also identifies your assets and financial documents for your family.
2. Funeral arrangements. A loved one might appreciate expressing her wishes about burial, a memorial service, where to send donations and organ donation.
3. Advance directive. When a loved one is too ill to make her own medical choices, the advance directive speaks for her. An advance directive often includes both a *power of attorney* and a *living will*, but that varies from state to state.

Power of attorney for health care. This legal document has different names in different states. It gives a person, usually spouse or family member, authority to make medical decisions about treatment and procedures for an ill patient if she is incapacitated, as determined by a physician.

Living will. This legal document specifies what a patient would or would not want done to keep her alive, if she is unable to express herself. Choices include resuscitation, artificial life support, tube feeding, dialysis, medications and palliative care.

"The importance of having an advance directive benefits not only the individual but the family members and other professional health care providers that may need to care for someone facing a serious or life-limiting illness," said J. Donald Schumacher, president and CEO of the National Hospice and Palliative Care Organization.

To download an advance directive for your state, go to www.caringinfo.org/i4a/pages/index.cfm?pageid=3289

It is never too early to think about filling out an advance directive, even if you are young and healthy. Your family will know what you want done in a medical emergency, and you can be assured your final wishes will be honored. ❖



TELLING YOUR STORY YOUR WAY

Paul Moore is dying but his spirit and faith could not be more alive.

By Jason Wright

At the insistence of a close friend, Paul Moore, 36, and his wife visited the emergency room with questions about his shoulder and neck pain. When tests revealed 40 tumors, Paul chose to endure radiation and surgery, including kidney removal and a hip replacement that nearly killed him.

“None of it worked,” says Moore, without a hint of bitterness. “We all have two stories to tell,” he says, stealing a glance at his wife, Joni. “I choose to tell mine in the best way possible — with grace.”

“Great things come from trials,” he says. “I’ve learned that depression doesn’t get me anywhere. I consider myself one of the luckiest guys on earth. What a blessing to have time to mentally prepare to see what I will see and to be worthy of the other side.”

Paul speaks lovingly of their two daughters: Ellie, 5, and Reese, 3, who are both on the autism spectrum. “I’ve written letters to them and we’re making videos,” he said, in hopes they will remember him.

Paul offers a message of hope to those who will never meet him, but may hear his story. “Please quit wasting time

with negative thoughts. Let your perspective change. It has worked for me. There are so many good people all around you. I’ve had to let those thoughts go and start driving in the slow lane. You can do this, too.”

Paul Moore is right — everyone has two stories. We could have spent our time together discussing sickness, treatments and heartache or used the time to talk about inspiration. With remarkable candor, the Moores are taking a chance that Paul’s journey to the other side might inspire someone else.

“Make a choice,” Paul says. “And always tell the most inspirational story you can. I view what I’m experiencing as a privilege and a blessing. That’s the story we want to tell.”

They’re doing that and so much more. Paul Moore has lived a grateful, faithful life, and he’ll die the same way. And while the timing may not be his to determine, he’s living and telling his family’s story on his terms.

And he’s telling it with grace. ❄️

Jason Wright is a New York Times, Wall Street Journal and USA Today bestselling author.

Why You Need Someone Who Will *Really* Listen

One of the most helpful things you can say to someone in crisis is, “If I had a magic wand, what would you wish for today?”

By Paula Spencer Scott

What did my mom and I talk about when she was diagnosed with a cancer that had already metastasized and defied treatment? The weather. Scrabble. What she felt like eating. Oh, my siblings and I also assured her that we loved her and that we’d take care of Dad, who had dementia.

But I wish I’d given her more openings to talk about things that were on her mind. Too late, I’ve thought of so many questions that I avoided while we were all so busy

trying to seem calm and normal about the whole abnormal, sucky thing:

- “How do you feel — no, really?”
- “What do you think about what the doctor said?”
- “Are you scared?”
- “Are you mad?”
- “Is there anybody you want to see or talk to?”
- “What would make things better for you right now?”



Those missed opportunities would have been a gift to her, I think now, an invitation to lay aside the motherly impulse to protect us and say what was in her heart and *really* on her mind (besides using all her letters at Scrabble). She might have resisted. Or more likely, she might have felt a kind of grateful relief — and ultimately made things easier for all of us.

It turns out that my regrets aren't unfounded. Experts in hospice and palliative care say that having someone who listens — really listens — is critical to well being and decision-making for those who are ill enough for palliative care, hospice care, or transitional care (from hospital to home, nursing home, or hospice).

Why being heard matters

When you're ill, feeling that you have a voice and perspective that's understood and honored is as important as any cure — and especially so when cures are uncertain or unlikely. Being heard on a deep level improves mental and emotional well being, peace of mind, and quality of life. After all, we all want this, all through life. Why should it be ignored in the crisis chapters of life?

Nobody makes care decisions in a vacuum, says Rafael Romo, RN, PhD, and a nurse fellow at the San Francisco VA who has studied this process. Research shows that only about 20 percent of people want sole control of these healthcare decisions. Most people want to collaborate with doctors and family. "When families listen and focus on the values and goals the person articulates, they can better support choices that match their wishes," he says.

But it's also important to realize this: What's uppermost on people's minds is rarely just the choice itself. (Should I sign up for hospice? Should I take the chemo?) Their main focus is on all the circumstances surrounding that choice and its outcome, Romo says: worries, fears, wishes, hopes, goals.

What kind of talking?

What kind of listening?

Dawn Gross, a hospice and palliative care physician in San Francisco, asks all of her patients receiving palliative and hospice care this heart-of-the-matter question: "If I had a magic wand, what is it you would wish for today?"

Her reason: Right up to the last breath, there's always ►





no one has asked me what I want.”
“That’s an invitation,” Dr. Gross says.

How to make it happen

*** Try to be sitting down.** In a hospital, that can be hard. But studies show that when doctors, for example, are seated, the patient’s experience of how much time is spent and the quality of the conversation, is greater. Focused face-to-face time says, “You matter.”

*** Be curious.** “When someone says, ‘this matters,’ don’t just say, ‘Got it,’” Dr. Gross says. “Say, ‘Let me be sure I have this...’ Assume nothing and be

as curious as a 5-year-old. The more specific you get, the better you understand what really matters.”

*** Don’t be too quick to shut down conversations that feel uncomfortable.** Romo says that families often unintentionally misperceive the sick person’s willingness to talk as a sign they’re giving up. “Mom might say, ‘When I’m gone...’ and before she can say more, her children say, ‘Oh no! Don’t talk like that!’ or ‘Don’t say that, I’m praying for a miracle for you!’ But if everyone talks like that, the person can feel forced into choices they don’t agree with,” he explains.

The path to “potentially intense, scary, but immensely gratifying conversations,” says Gross, is to invite them. “We get afraid of emotion. We ask, ‘How are you doing?’ but don’t always mean that. It’s better to say, ‘What is it you want to say and what is it you want me to hear? You have full permission to talk. I’m ready to hear it.”

*** Be honest.** If you don’t know an answer, say, “Let me find out and get back to you.” That’s empowering.

*** Consider using tools to help.** One way to make such conversations easier is through conversational helpers developed by people experienced in end-of-life decision-making. A card game called “Go Wish,” by the nonprofit

more that can be done — and the person at the center of the situation knows exactly what the “more” is that he or she most wants. It’s different for everyone, and it can change from day to day. Maybe it’s less pain or less anxiety. Maybe it’s to make it to a daughter’s wedding or to see their garden. They may want to have a bath. Or be prayed for. Or ...

...the possibilities are endless. But first we have to ask.

Most people *want* to express what matters to them, she says. The key to hearing them is to make the time and space to invite such conversations.

“Really great listeners help you hear yourself, and help you both to realize what matters most,” she says.

Hospice workers are skilled at this kind of open, nonjudgmental listening and can provide a valuable outlet, as well as help people realize the goals they confide.

Ann Beetner, who became a hospice volunteer after her husband’s death, understands this from firsthand experience. “As families, we often shush conversation about dying. But I find that people who are dying usually want to talk — about their fears or hopes or the fact that their hovering daughter is driving them crazy,” says “We welcome it. We can be honest with them and give them a voice without feeling like they’re hurting anyone’s feelings.”

Powerful listening deeply also means being attuned to what’s unsaid. “It’s not always an explicit request,” Gross says. Her father, at the end of his life, would say things under his breath like, “I don’t understand why

Coda Alliance, for example, helps people find the words to talk about what's important to them when they're very sick or dying. (There's a free online version available at gowish.org.) My Gift of Grace is a similar conversational card game. Sample questions: "What music do you want to be listening to on your last day alive?" "In order to provide you with the best medical care possible, what three non-medical facts should your doctor know about you?"

*** Talk early — and talk often.** Ideally, of course, we share with our loved ones over time — even before illness — to

know what they want. But even if you're in the minority of families who do this, situations change. And with them, so do symptoms and priorities. "A conversation has to continue over time," Romo says. "It can't just happen once."

Above all, assure the person who's at the center: "I'll guide you based on what you say is important, but ultimately you are in charge." ✂

Paula Spencer Scott is the content chief of the family resource Kinstantly and the author of *Surviving Alzheimer's Practical Tips* and *Soul-Saving Wisdom for Caregivers*.

IN *Praise* OF EARLIER ADMISSIONS

Earlier is better when it comes to almost all aspects of hospice and palliative care — and not just talking about these options theoretically. Actually enrolling early enables patients and families to take fuller advantage of what such care can offer.

"Too little, too late" describes most people's experiences, however. The median hospice use, for example, is 18.5 days. Sixty percent of patients and caregivers wish that they'd been referred to hospice earlier, according to surveys by the National Hospice and Palliative Care Organization. Several studies have found that patients with many terminal diagnoses (looking at lung cancer, gallbladder cancer, and breast cancer) live longer when receiving hospice care vs. standard care.

"You can't enter hospice too early or stay too long," says Dawn Gross, MD. And no formal qualifying criteria are needed for palliative care. Anyone can ask for a palliative care consult at any point in a serious illness.

Among the benefits to early admission:

1 Less pain, which makes it easier to focus on priorities. Many people underestimate the extent to which pain saps energy and spirit. Effective medication and symptom management make more of everything else possible.

2 Less stress, which makes space for more joy. Sharing the burden of care with professionals who understand how to establish preferences and needs, and navigate care choices, can ease worry and uncertainty for patients and families alike.

3 Help with costs and other practical hassles. Medication, equipment, and supplies are typically paid for in hospice, and patients are spared the hassles of getting to medical appointments. Experts are on hand to help with things like advance directives and funeral planning, too.

4 Help with focusing on personal goals. Families can do this, of course. But hospice and palliative care teams are trained to provide full emotional, psychological, and spiritual support.

5 A sense of closure that's more meaningful for everyone involved. When the focus of care is centered on what's important for getting the most out of life right now, people tend to be able to turn their attention to healing or deepening relationships, completing life's business, offering thanks, and being thanked — all deeply valuable life experiences.

The ‘Right Way’ to Love

Authentic love is beautifully complex — and brutal, funny, and sacred.

By Paula Spencer Scott

Nina Angela McKissock was setting down her nursing bag and taking off her coat when a woman’s voice hit her ears:

“...and who’s gonna teach these kids to drive...and you promised me, PROMISED ME that we were gonna grow old together!! Just go!”

The woman’s 40-year-old husband had come home from the hospital. His — their — three-year cancer battle was winding down. “He was deflated, physically weak and sorry as could be,” says McKissock, a home hospice nurse.

She stood in the hallway and opened her arms to the stressed, spent wife. “She had reached her limit of fear, exhaustion,” she explains. “They loved each other deeply. Was it patient love? Not at that moment. Was it kind? Nope, not right then. Did it endure all things? Nope; too scary. But even if love doesn’t look the way we think it should look, it is still love.”

What’s the right way to “be” around someone who’s facing a critical or terminal illness? Start by letting go of the word “right,” suggests McKissock, author of *From Sun to Sun: A Hospice Nurse Reflects on the Art of Dying*. Focus on being yourself.

“Love has many faces,” says McKissock, who has seen them all across her 40 years as a nurse. Every person, and every family unit, expresses love in an individual way

“Love has many faces”

based in habit and shared history, family traditions or cultural norms. And those same individual patterns shape how we make decisions, support one another, and cope with stresses and transitions.

The stressed young couple

McKissock had come to help were deeply attached — close enough that she could express her rawest feelings right in that moment knowing her husband loved her anyway, as she loved him. Were they her last words to him? No. “Great, deep, honest love is beautifully complex — and delicious, brutal, funny, and sacred,” McKissock says.

The surest way to express love to a dying friend or family member is by being authentic, she says. “If the person knows you well, they can read your eyes and voice and can tell you’re just faking it. If your heart is breaking, say it. If you are worried, say it. If you don’t know what to say, say that! The dying have very high B.S. detectors, so be yourself.”

Equally important: Accept them exactly as they are and allow them to live out their life as they wish, she says. “And don’t wait to tell someone you love them.” ❄

Spiritual Care Conversations

By Dr. Harold Koenig

To better understand the spiritual needs of the terminally ill, academic researchers have been studying what patients say they want to determine how to improve their quality of life.

The physicians at Harvard's Dana Farber Cancer Institute in Boston found that while 88% of patients said religion was important, only 72% said their spiritual needs were supported by the medical system. Patients who felt spiritually supported expressed a better quality of life.

In the *Journal of the American Medical Association*, these same researchers reported their study on the use of life-prolonging care requested by the patients during the last week of life, such as mechanical ventilation, cardiopulmonary resuscitation and hospitalization in the ICU.

They found that such treatment was more common in those who were *more likely* to use religion to cope. To explain this seemingly inconsistent behavior, researchers discovered that this was occurring primarily in patients whose "spiritual needs were not being addressed by the medical team."

Among those using religion to cope whose spiritual needs were being met, the likelihood of receiving hospice care increased 5-fold and aggressive care decreased by 72%. The cost of care during the last week of life for those whose spiritual needs were being addressed was half the cost of

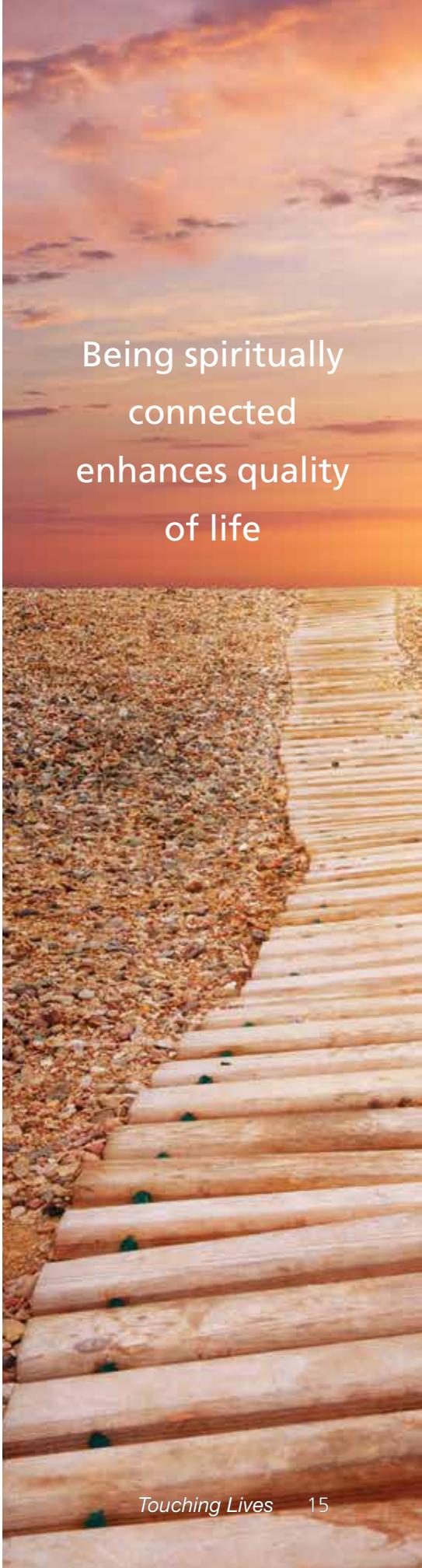
patients whose spiritual needs were not, and among minorities, it was *one-third* the cost.

Those whose spiritual needs were not being addressed were often not communicating with their physicians about those needs. Physicians were not asking and patients were not telling. Many nurses and doctors often avoided the subject rather than initiate a conversation in a sensitive and respectful manner which resulted in many patients spending their last days unconscious or afraid.

To better understand how to address spiritual needs, Duke University's Center for Spirituality, Theology and Health (www.spiritualityandhealth.duke.edu) partnered with Adventist Health System to develop spiritual care teams in physician practices to identify and address the whole-person spiritual needs of every patient (<https://faithinpracticemed.org/>).

This effort is committed to identifying and meeting spiritual needs that respect the powerful religious beliefs of patients and honors each person's unique journey. We believe that medical and spiritual care delivers the best kind of medicine for all patients in every life circumstance. ✘

Harold G. Koenig, M.D., is Professor of Psychiatry & Behavioral Sciences and Associate Professor of Medicine at Duke University Medical Center; Adjunct Professor, King Abdulaziz University, Saudi Arabia and Adjunct Professor, Ningxia Medical University, P.R. China.



Being spiritually
connected
enhances quality
of life

(continued from page 5)

together and bonded over those little moments that make people a family. His mother, he said, clearly enjoyed it even though she wasn't always able to respond.

"We laughed and the sound of laughter is something that I could see eased her," he says. Laughter is "a shared expression of connection and love. Laughter is so much a part of most loving relationships. It would be a terrible mistake to deny that."

With his father-in-law, joyfulness took the form of honoring the man who was the anchor of his family. Caperton say family members sometimes talked with him but also spent lots of time talking to each other.

"We were there as a testament to the love and joy and the things we all shared," he says. "No one had to instruct the family. It just emerged that we are here for some fellowship and a really wonderful experience to share as a family."

Caperton noticed that once all three relatives had accepted "that this is reality," they seemed to live "more successfully and deliberately," as if they finally recognized what really mattered.

"Once they accepted it, it was, okay, this is it," he says. "Suddenly it was about how much we love each other, how connected we are, how much we cherish the moment. "What we make of those moments becomes the most important thing that we can do. Some of these memories seem to be the most precious. Strangely enough, joyful laughter filled those moments."

Living a joyful life isn't for the faint of heart, Caperton says. It doesn't just happen. It takes "real intentionality, some real determination" to achieve joyfulness.

"What I'm trying to communicate is a sense of purpose, the fulfillment that comes from a deeper place and really knowing you are living the kind of life that has meaning," he says. "Joyfulness isn't denial; it's defiance. It is the defiance of harsh realities and difficulties."

Nor is it for people who think being joyful means not dealing with life's realities. Contrary to what others may think, joyful people don't go through life wearing rose-colored glasses or ignoring reality.

"That, to me, is one of the biggest misconceptions when you talk about joyfulness," he says. "Not only am I in touch with reality, I am seeing that some realities are pretty harsh and unpleasant. So I have to work very hard to think right."

If you want a joyful life, Caperton says, you have to model joy in everything you do. Make your work a more joyful place and give the joy that you want to receive in your relationships with other people. Cultivating joy in a world where the 24-hour news cycle is filled with violence and evil is hard. But if you look closer you will find the good and joyful.

"There are a lot of folks who do good work," Caperton says. "There are a lot of people who do things that bring dignity and love and caring and make the world a better, more joyful, kinder place." ✨

Robert Calandra is an award-winning freelance writer and book author.



Living Our Mission, Our Foundation

Charitable gifts to the Harbor Hospice Foundation support our mission in many ways, impacting our community, patients and family caregivers.

How does the Foundation support the mission of Harbor Hospice?

The Foundation builds relationships that foster philanthropy to support Harbor Hospice's operating and long term capital needs. For patients who are uninsured or underinsured, financial assistance with patient care costs including room and board at the hospice residence is offered. Volunteer and grief support program costs which are not covered by insurance are likewise funded by charitable giving to the Foundation.

What are the programs of Harbor Hospice?

Hospice Home Care — We provide hospice care wherever the patient calls 'home', i.e. a private residence, assisted living, adult foster home or nursing home.

The Leila & Cyrus Poppen Hospice Residence — Specialized inpatient care is provided by our trained staff 24/7 to manage pain and other symptoms. As with any home, funding for maintenance and capital improvements is needed.



Palliative Care — This program moves our expertise upstream to help patients and families have the best possible quality of life and understand their options and choices when dealing with any complex diagnosis. Clinical education is vital to the success of this program.

Advance Care Planning — Harbor Hospice believes everyone should voice and document their end of life wishes. Our Advance Care Planning initiatives offer clinical and community education with specific instructions on these difficult conversations and appropriate documentation.

Volunteer Services are at the heart of hospice care. Comprehensive basic and patient care training for community members wanting to give back is provided several times per year. Harbor Hospice is a national partner with the *We Honor Veterans* program and includes a pinning program for veteran patients and their families.



Bereavement Services — Our trained professionals offer resources to individuals and families on their

journey through grief, and include individual, group and special programs such as our children's grief camp, Camp Courage.

What are the ways to give?

There are many ways to support the work of the Foundation.

- Direct Donations from individuals, businesses, service and church groups
- A Planned Gift — The Legacy Circle acknowledges individuals who support through charitable gift provisions in their estate plans, trust, IRA, life insurance policy or appreciated stock
- Memorial Giving — A meaningful way of honoring the memory of a loved one



- Honorary Giving — A special gift to thank someone who has touched your life in a special way
- Special Events — Raising awareness and funds through annual events including Ride to Remember and Harbor Hospice Regatta ❧

A Father's Walk Through Grief

by Susan Newhof

Dan Begue can laugh a little now when he describes his beautiful daughter, Danielle Nash. “She lived life like her hair was on fire,” he says, and we chuckle together at that joyful image. Danielle was a self-assured youngster who grew into a woman with drive and determination. In a period of a little more than two years, she graduated with a bachelor’s degree in early childhood education, started a business, bought a home, got married and had two beautiful babies. At 26 years old she was at the top of her game. Then cancer brought it all to a sudden stop.

“The people with Harbor Hospice told my wife Sherry and me that grief counseling was available to us, but I didn’t think it was necessary,” remembers Dan. “I didn’t know what it could do for me, so I didn’t give it a second thought. But my grief turned to anger and it kept getting worse. I couldn’t shake the thought that I should have been able to do something to stop Danielle from dying! I felt useless and isolated, spiraling endlessly into a dark well with no end in sight. I was in a general state of *what’s the point...why bother?* It didn’t take much to set me off,

and my wife and those closest to me bore the brunt of it.” A year later, suffering a kind of emotional pain he didn’t know could exist, Dan abruptly left work one day and drove to Harbor Hospice to ask for help. It was a sobering turning point.

“I decided I needed to do something before I ran myself into a tree,” he says quietly.

“People often expect that their pain will go away, that they’ll get over it,” says Harbor Hospice grief counselor Pamela Wingard. “Time does not always heal all. And when one tries burying their grief, it can get worse.”

When a death is *out of order*, when parents bury a child, instead of the other way around, grief can get even more complicated. Anger is a common reaction, and it bubbles up at unexpected times. Hearing someone talk about a family member they’re taking for granted can trigger it. A new loss can also bring on strong feelings about a loss in the past.

After several months, well-meaning friends often assume the person is over their grief, that they’re ok. Yet, months later is when that individual needs the *most support*.

Harbor Hospice grief counseling takes family members through the first year of holidays, birthdays and anniversaries without their loved one. Help comes in the form of one-on-one conversations, group discussions, and things to read that provide tools for managing grief. Counselors check in at three and six months to see how the family is doing.

“We help family members understand how *normal* their waves of feelings are and what to expect,” says Pamela, “because this great loss will likely affect other parts of their life and other relationships. If someone is struggling with severe depression or having trouble sleeping, if they have lost interest in things they once enjoyed, if there are substance abuse issues or behavior problems, we can make referrals for additional help.”

“I figured the holidays would be tough,” recalls Dan, “and they were bad, but it was the everyday stuff... the little things that immediately made a connection to Danielle that I could not shake. Pamela took the time to try to get to know me. She helped me understand that we did everything we could to help Danielle, that we were not alone, and that the feelings and reactions I was having were not unusual, at all. In fact, they were a necessary part of grieving and healing. The process would take time and attention to re-think and re-learn a new relationship with Danielle — one not of a physical but of a spiritual nature. Pamela also suggested that some temporary medications could help me get through the low spots until I was better adjusted to this new reality — something I would never have considered.”

“Guys don’t do this well,” Dan admits. “We think it’s some kind of weakness to ask for help. But grief can consume you. This kind of overwhelming grief feels like a freefall, like you have absolutely no control of your life or your ability to care for your family.” His advice is to contact Hospice.

“Losing a loved one is so unbelievably tough,” says Amy Cunningham, who provides patient care alongside bereavement counseling for Harbor Hospice. “We give our undivided attention to exactly what an individual is feeling. We are a constant presence for them, and we help them cope.”



“Don’t wait until you *think* you need help,” Dan says, with the certainty of one who has walked that treacherous path. “Understand that this is probably the worst trauma you’ll ever experience. This is not the time for on-the-job training. I wasn’t ready for counseling three months after Danielle’s passing, but I waited too long, and for some, waiting too long can be too late. That unending grief and anger can turn into dangerous, destructive behavior.”

“Don’t over think it,” Dan adds, hoping his story can help others. “Don’t destroy your life because of grief. Hospice counselors will recommend good books that can take you step-by-step out of your isolation. You might not be ready to talk, but you might be ready to read, and you’ll begin to understand that you don’t need to go through this alone. Hospice is here for you.” ✕



Roger Morgenstern

Grateful family, donor and Harbor Hospice Foundation board member

"In reading our mission statement, it sums up our family's experience: Harbor Hospice brings empathy, expertise and excellence to end of life caring. From the front desk volunteers to Dr. Harriman, all the wonderful doctors, nurses, aides and other staff both at our parents' home and at the Poppen... it was evident to my entire family. If you needed something or someone, it was done before you even had to think twice. I can't count how many times I enthusiastically or tearfully said 'thank you' and 'you folks are amazing.'"



The Harbor Hospice Foundation

Because we know you believe that living well includes dying peacefully, in comfort, and with dignity, we created the Harbor Hospice Foundation and invite you to support essential end of life care for individuals at home and at The Leila & Cyrus Poppen Hospice Residence.

You can contribute in many ways that add special meaning for you, such as designating a memorial or planned gift through a will or trust, providing a workplace sponsorship, and by participating in special events.

Your compassion connects you to the professionals who devote themselves to patients and families in hospice care, and your gifts make certain that Harbor Hospice will never have to turn away a patient for lack of ability to pay. Please visit our website HarborHospiceMI.org, to learn about all the ways you can support our mission.



Main Office
1050 W. Western Ave. Suite 400
Muskegon, MI 49441
800.497.9559
HarborHospiceMI.org